
INTRODUCING PARENTS TO THEIR ABNORMAL BABY

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The two papers included on this topic come from the United Kingdom and present information related to the situation there. The results should be interpreted with caution by those working elsewhere. Nevertheless, professionals need to realize that criticisms of themselves and their services by parents should not be dismissed, and that in most cases the situation can be improved. These papers recommend possible improvements for the United Kingdom. Listening to parents, accompanied by sensitive research can lead to the development of similar sets of recommendations in other countries.

INTRODUCING PARENTS TO THEIR ABNORMAL BABY¹

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One in 40 babies is born with a major abnormality and yet we really know very little about how to tell the parents about this. That we need to learn how to do so and that we are not effective at doing it, is clear from Hogg's study in which he showed that 80% of the parents of severely retarded children did not remember ever having been told officially about the retardation (1).

Childbirth is a very emotional occasion for parents. If the baby is abnormal, additional very complex emotions arise and the process of the birth may be regarded as having been useless. The labour and delivery are almost always considered by the parents to have been difficult if the end result of the labour is a dead or deformed baby. The whole situation is made more difficult for the parents by the attitudes and reactions of the people around them. The professionals, whether they be doctors, nurses or midwives, may be less ready to go and talk to the mother of an abnormal baby than to the mother of a normal baby. The parents of an abnormal baby are very sensitive and will notice this and interpret it as being shunned. A pregnant mother gets generalized public approval with comments such as "You look radiant" or "Pregnancy suits you", with people going out of their way to talk to them and ask them how they are. However, if the baby is deformed or dies, word gets around the community, and people do not know what to say to the mother and so avoid her. They may also be wondering what the mother did wrong to cause the deformity or to deserve it happening to

her. There are basically three situations in which bad news has to be brought to parents.

The first, which is becoming more common as technology improves, is where an abnormality has been detected on antenatal ultrasound scan. This situation will not be discussed further in this paper.

The second situation where parents need to be told bad news is where a previously undiagnosed abnormality becomes evident at birth. Such an abnormality may or may not be evident to the parents. If the abnormality is obvious, then the professional attending the delivery will have to give a simple explanation of the abnormality. If it is not obvious to the parents, then I think that they should be told as soon as possible by the most senior person available. If the professionals attending the delivery are unsure of the diagnosis, e.g. in a baby with suspected Down's Syndrome, then the Consultant Paediatrician should be called to confirm or refute the diagnosis.

The third sort of situation which arises is where the abnormality becomes obvious to the professional in the course of the first days or weeks, e.g. after perinatal asphyxia when normal feeding does not become established. It is very difficult for the parents to believe that what their child is doing is not just a variant of normal and temporary behaviour, as to them the baby looks and acts normally. They may try to find plausible excuses for why their baby is behaving as it is. They may also put an inordinate amount of weight on the child achieving one of the milestones which have been mentioned as

¹ Adapted from an article originally published by Duphar Medical Relations, UK

pointers to an underlying chronic problem. For instance, the fact that an asphyxiated baby finally successfully bottle feeds may be interpreted by the parents that the baby has become normal and that the damage has been repaired or that the diagnosis was always wrong.

The method of telling

1. Where to say it

If possible the parents should be told together. It must be in a quiet room where there will be no interruptions. One or more other professionals can be present, preferably those who have already been involved with the parents. If many people are present, then this can inhibit the parents from voicing their most intimate fears. If the mother is single and the boyfriend is no longer important to her, then somebody else who matters to her, such as her mother or a close friend, should be encouraged to be present. It is best to tell the parents while they have the baby in their arms.

2. What to say

Parents are usually aware that there are problems because they are very sensitive to the atmosphere and will see from the faces of the professionals that the news is bad. It is unnecessarily cruel to walk into the room with them and to spend a long time coming to the point. It is important to tell the truth. After introducing yourself, you should begin with a brief and simple explanation of the problems, pointing out those features which make you think that their baby is abnormal. A balanced view of the significance of your diagnosis for the baby and themselves should be presented. This should be neither over-optimistic nor over-pessimistic. They should be given something positive to hang onto, so that they can have some hopes even in the most hopeless and awful situation and also have something to be proud of. There is a phase through which we almost all pass, when inexperienced, in which we paint a picture as black as possible in explaining problems to parents, to make sure that we have got the message across. This is unnecessary because parents can become too depressed and they have enough to cope with. A balanced explanation, without getting too involved in all the details of the special needs that the baby may have in the future, is all that is required at first. For the first six months the parents will probably only need to give their child what any other baby would need - love, food, warmth and a clean nappy. Later the parents will find out what the particular needs of their child are and

will have to adjust to these as they become aware of them.

It is also important, even in the first interview, to try to allay the feelings of guilt that the parents, particularly the mother, may have. Parents almost always feel that they have done something wrong, either during the pregnancy to cause the problems or in their "murky pasts", for which this is punishment.

They may also feel very guilty about their reaction to the abnormality and their feelings of rejection and possibly revulsion. These feelings should be talked about openly. They will be discussed in more detail later.

3. How to say it

It is important that the parents are given frequent short interviews rather than that they are told all in one long interview. They usually only take in one or two facts and then do not hear anything else for the rest of that interview. Having told the parents in the initial interview, you should give them time alone for the information to sink in and return in a few hours to answer any questions and to go over any important points again.

You should talk to them looking them straight in the eye. Parents rightly complain if they are told the bad news while the doctor is looking out of the window or playing with his pen. They need to be told sympathetically and humanely.

It may also be helpful if you see both parents individually at a later stage. The father particularly may have special fears about his wife which he cannot express in front of her. They may both have fears about the baby which they do not want to mention in front of their partner because they do not want to worry them further. There may also be things about which they feel very guilty, but which they have withheld from the partner, such as a previous termination of pregnancy or an episode of venereal disease in the past, which they may feel has caused the problem in some way.

4. When to say it

In the past, many professionals have advocated waiting before telling the bad news. I have even heard of one paediatrician who waited nine months before imparting the diagnosis of Down's Syndrome to some parents. This attitude probably stems from two main concerns. Firstly, there is a feeling that it may be a good idea to allow parents to bond with their baby and to give them a period of blissful ignorance when they can enjoy their baby before facing up to

reality. Secondly, I think that the motive may be just putting off the very unpleasant task of telling the parents - and it is never pleasant - in the hope that it will not be necessary; unnecessary either because the parents have noticed the problem for themselves or because another professional has told them.

In a study of parents who had been told the diagnosis of Down's Syndrome in their baby at least one week after the diagnosis had been made, Cunningham showed that this delay was a major cause of complaint. Parents found it acceptable to delay giving the diagnosis only if the mother was extremely ill after delivery, if the diagnosis was genuinely uncertain and chromosome results were awaited, or if it was impossible to see the parents together.

Personally, I do not usually wait for chromosome results, but express my suspicions to the parent on clinical grounds alone, if I am reasonably certain of the diagnosis. I will go into the hospital even in the early hours of the morning to tell parents that their baby has Down's Syndrome or whatever the diagnosis is. It seems to be unnecessarily cruel to allow the father to give the family the joyous news that they have a lovely son or daughter and then have to tell them some hours later that the baby has Down's Syndrome.

[Once they have been told the news parents may want to telephone their families or friends. We have a special quiet sitting room with a telephone in it from which the father or mother can telephone their parents, relatives and friends. They may well want to cry and it is obviously unsympathetic to expect them to use a public call-box in a hospital corridor or even a phone in a busy office or nursing station. Some parents prefer a professional from the hospital to contact the family and so I offer this.]

I have been unable to find any research on how the parents of an abnormal baby bring the news to their families. There must be good and bad ways of doing it, but I find it difficult to give them advice on how best to do this. I assume that the same general rules apply as for a professional telling the baby's parents.

Seeing the baby

It is extremely important that the parents see the abnormal baby. The human imagination knows almost no bounds and can dream up far more horrific and upsetting abnormalities than anything that nature creates. Once the parents have seen their baby they have a clearer picture in their own mind and this reduces nightmarish flights of fancy.

There are many ways of introducing the parents to their baby. I think that the best way

is to do it absolutely naturally, handing the baby to them directly after the delivery as though there was nothing wrong, but as you do so, explaining what the obvious abnormality is. If the professionals involved do not show revulsion and rejection then the parents are less likely to do so.

If the abnormality is considered too shocking then it is best if the baby is wrapped in such a way as to minimize the defect and a brief, simple explanation of the problem given as the baby is handed to them. They should then be given a few minutes alone with their baby in their arms. They will usually unwrap the baby to discover the abnormalities at a speed with which they can cope.

Parents refuse to see their baby most commonly where an abnormality has been noted on an antenatal scan and they have not been properly counselled at the time. If the parents refuse to see their baby, they should be very strongly persuaded to do so for the reasons mentioned above. I have had to bully parents on many occasions to do so and all of those have subsequently thanked me. In my experience neither anencephaly nor even the collapsed skull of a hydrocephalic child delivered by destructive delivery are too horrific if the baby is properly wrapped and the professional's approach is sympathetic. Even severe degrees of maceration do not seem to matter if the parents receive an explanation of what it is. They only seem to see the facial features of their baby.

Should the parents refuse absolutely to see their baby then their wishes should be complied with at the time. They usually do this because they are very frightened. There are a number of ways to help persuade them to see and cuddle their baby and to conquer their fear: by repeated short visits stressing the more positive things about the baby, and by making him or her a person, e.g. "she's got a lovely face" or "he's a real fighter" or whatever seems appropriate. If the parents have given the baby a name then this should be used as much as possible in conversation. They should always be strongly persuaded to name their baby so that they can talk about him or her more easily. They should use a favourite name and not keep the name which they were going to use for the next, hopefully normal, baby.

[Polaroid pictures may be taken of the baby. If the abnormality is very obvious and upsetting then they should be taken either from very close, so that they are blurred, or from far enough away to make the abnormality less obvious. They should be taken of the baby as a baby and not as one would for a medical textbook. Very often parents can be persuaded to look at pictures of their baby and once they have seen the problem is not as horrific as they

imagined, then they will see and cuddle their baby. Parents who refuse even this should be told that pictures of their baby are available, and these should be stored in the notes.]

Sometimes one parent can be persuaded to see the baby and can persuade the other to do so in due course. Another technique which occasionally works is to draw the abnormality for the parents. This may just be sufficiently detached for them to be able to cope with and then once they have seen that it is not as bad as their worst fears then they will eventually see their own baby. They may be persuaded to look at pictures of someone else's baby with a similar condition.

Unfortunately there are no books available of pictures of babies who happen to have major defects as babies. The illustrations in medical texts are taken to accentuate the defect and to minimize the baby.

Most parents benefit from receiving some written information about their child's condition. We should try to have something available for the more common conditions. This is no substitute for talking to the parents, but it is useful for them to have something to look at when they feel less shocked and in a more receptive state. They may also use it as a way of opening a discussion with their friends or relatives. Some parents may search the public library or any other source they can find for information about their child's condition. Unfortunately this information, if and when they find it, is often out of date, and may be totally inappropriate and misleading. It is easy to overload parents with facts because they are articulate, ask penetrating questions and want to know all aspects of their child's condition.

Many parents will benefit from being introduced to other parents of babies with a similar condition. This does not have to be immediately after the birth, but should be offered, if possible, and may be taken up at a later date. There are potential problems because it is very difficult to find two babies who are alike in all aspects of the condition and one may develop a complication that the other does not and this will lead to extra anxiety, e.g. leukaemia in Down's Syndrome.

The parents' responses

How do parents react to the news? Cunningham divides their responses into long term feelings and immediate reactions (3). "Feelings" are emotions that endure, they are there all the time and never go away. "Reactions" are more temporary and are a coping mechanism. There are innumerable feelings, such as guilt, embarrassment, blame, shame, anger, grief, loss, sadness, yearning, futility and many others.

Reactions are fewer in number but equally important. Shock is universal. It must be truly shocking to learn that the lovely baby you had been expecting is in fact abnormal. Shock is often rapidly replaced by numbness. This is much like the grief reaction where the parents have blown their emotional fuse and do not feel either happy or sad any more - they just do not feel anything. This may be followed by denial. They deny that this is happening to them. They feel that it must be happening to someone else and that the doctors or nurses must have made mistake, or they feel that it is all a nightmare and that they will wake up soon and all will be well. They may also feel very angry.

Rejection is probably less common than might be supposed. In one study only 4% of parents said that they felt rejection (4). However, only 29% of the parents in this study had been told in the first week after birth, and many were told considerably later. Those who do feel rejection may also feel at the same time that they must protect their poor, helpless baby who has done no wrong.

It is tempting to consider the parents' responses in phases. This has inherent problems because using the word "phase" suggests a progression towards normality and if the abnormal child survives there may never be normality again for those parents. However, it is a useful way in which to describe parents' responses and Cunningham and Jupp describe four phases (3).

- The first phase is that of shock, numbness and denial.
- They then move on to a reaction phase where they are attempting to understand the disability and regain control of their lives.
- The third phase is one of adjustment or adaptation when they are asking "What can be done?" or "How can we get help?" At this stage they are beginning to regain their self esteem.
- The final phase is one of orientation, where they are beginning to establish new routines and life begins to take on a new "normality" and they appear to have adjusted to their problems and to cope very well.

Parents have to face many difficulties, not least the reactions of the people with whom they come into contact. If their baby is obviously abnormal, then some people may approach them in the street and ask them what they did wrong - "Did you fall during pregnancy?" or "Did you drink?" This can be very hurtful.

Follow up

The parents should be seen several times in the hours and days after the disclosure of the diagnosis. It is also vital that the parents are introduced to professionals from the community health services while they are still in hospital, so that they know that they will not be left isolated and without help once they go home. It is helpful for the parents to be able to discuss with them the various agencies and people from whom they can expect help and support.

Parents do not really distinguish between practical and emotional help, they just find who helps them and that is the person that they rely on. They need to know, or be able to find out, who the appropriate person is to turn to for help and to answer their questions.

I believe that the timing and the way in which the parents are told about the problems initially have a profound effect on the way in which they subsequently use the available services. It is clear from Cunningham and others that parental satisfaction is more dependent on the way in which they are told the bad news than on the news itself (4).

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TELLING PARENTS THEIR CHILD HAS A DISABILITY²

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In 1992 The Spastics Society of the UK conducted research on parents' experiences of the way in which their children with disability had been selected for possible special schooling (Spastics Society, 1992). Although not the object of the research, a large proportion of the parents, quite spontaneously needed to talk to the researchers about how they were told the diagnosis (Spastics Society, 1994). They found a similar phenomenon with parents of older children who, 20-30 years after the diagnosis, still needed to talk about it (Spastics Society, 1993). Most professionals working with such families have met the same situation. I certainly did in the late 1960s and as a consequence began a series of investigations into disclosure and the early needs of families of children with Down's Syndrome (Cunningham et al., 1977; Cunningham et al., 1984).

Such recollections by parents suggest that many have unresolved difficulties which may continue long after the disclosure. Two themes are apparent. Firstly, a minority of parents express feelings about the child's disability - sadness, loss of what might have been, why it happened. Several studies have described this issue of long lasting feelings such as chronic sorrow (Olshansky, 1962; Wikler et al., 1981) and have pointed to the need to understand parental adjustment or adaptation to the diagnosis of disability in their child (Cunningham & Davis, 1985a.)

The second theme is reflected in the many criticisms voiced by parents about how they were treated at this time. They often appear to have a cathartic need to recount the experience and seek confirmation that they were treated poorly.

This suggests we need to consider more carefully the procedures used in disclosing the

diagnosis. There is a considerable literature about this issue. I have collected over thirty studies starting in the late 1950s to the present day from many different countries and continents focusing on different disabilities and child illnesses (Cunningham, 1984; SCOVO, 1988). Between 40% to 80% of the parents interviewed expressed dissatisfaction with how they were told.

The criticisms expressed are all very similar and fall into three broad categories:

1. **The manner of the person giving the diagnosis;** for example, unsympathetic, cold, insensitive, expressed in language too difficult or vague to understand;
2. **Problems with information;** for example, lack of information and guidance about the diagnosis and what could be done. Highly negative and often misleading, contradictory and inaccurate information. Being denied information.
3. **Organisational aspects;** delay and difficulty in getting access to help, lack of privacy, lack of co-ordination between services (Cunningham & Davis, 1985b).

Despite documentation from the 1960s (Tizard & Grad, 1961; Wolfensberger, 1967), the emergence of guidelines for good practice (McMichael, 1971; Spain & Wigley, 1975) and advisory packages by many voluntary groups (such as *Shared Concern* - video and booklet - King's Fund, 1987) change within the UK appears to be very slow indeed; nor does the situation appear to be better elsewhere.

There appear to be some common beliefs which are barriers to change. These will be addressed before outlining recommended procedures.

² Originally a chapter in: Mittler, Peter and Mittler, Helle (eds) (1994). *Innovations in Family Support for People with Learning Disabilities*. Published by Lisieux Hall, Whittle-le-Woods, Chorley, Lancs. PR6 7DX, UK. (ISBN 1-870335-15-5)

Barriers to Change

The lack of implementation of good practice is mainly due to the belief that there is little one can do to improve the situation. Jacobs (1977) reports that doctors were unwilling to admit that they had told patients badly and explain the criticisms in various ways. These doctors suggest that parent recollection is confused at this moment of emotional upset and that later recall does not accurately reflect what happened at the disclosure. The parents' criticisms are thus considered unreliable and are not taken seriously. It is certainly true that many parents find it difficult to remember all the information provided at this time. In fact a major criticism that parents make, is that they are given insufficient time to assimilate information. Their recollections however are usually characterised by vivid details and strong emotions. In this, their reactions are similar to those described in research on 'flashbulb' memory about recall of major emotional events which concludes that emotional and life impact at the time are better predictors of clarity of memory than the subsequent retelling of the story (Rubin & Kozin, 1984). Studies have also found high agreement between parent descriptions of how they were told the diagnosis of Down's Syndrome shortly after the event and several years later (Cunningham et al., 1984; Gath, 1985; Carr, 1988). Thus one should accord some degree of reliability to parental observations of how they were told.

More serious is the suggestion that parental recollections about the disclosure are distorted by internal and pathological factors caused by their anger and resentment about it. This pathological model or interpretation is not helpful. By explaining the behaviour in terms of untreatable factors, it obstructs the search for alternatives.

There is evidence that contradicts this view. Certainly, not all parents criticise the way they were told. Some were quite satisfied and frequently very grateful for the way they were treated. Unlike those who felt they were told badly, these parents were happy to speak with the professional involved again at later dates and maintain a supportive relationship (Cunningham & Sloper, 1977).

A common finding is that parents are generally very aware of and sympathetic to the difficulties professionals experience. They readily forgive instances when problems occur with organisational aspects of being told the diagnosis, as long as they feel they have been given justifiable reasons for this and kept informed of what is happening (Cunningham et al., 1984; Cottrell & Summers, 1990; Sloper & Turner, 1993a).

Research evidence

The second source of evidence that criticism and dissatisfaction is not inevitable, comes from research studies (Cunningham et al. 1984). Using guidelines and survey literature (Spain & Wigley, 1975, Cunningham & Sloper, 1977), an 'ideal service' was designed with a consultant paediatrician and a specialist health visitor who had previously been trained to provide early family support and intervention with infants with Down's Syndrome. Between 1978-1980 there were 15 babies born with Down's Syndrome in their district hospital which was provided with the 'ideal service' in addition to the usual type of early intervention after discharge from hospital. Twenty-five Down's Syndrome babies born in adjacent health districts acted as a control group and these received the same usual type of early intervention following discharge from hospital but did not receive the additional 'ideal service'. All parents were interviewed by an independent researcher when the babies were six months old. Of the 15 from the "intervention" hospital, four did not receive the ideal service because of a breakdown in policy when the hospital registrars changed and the consultant was on leave. No statements of dissatisfaction were expressed by the parents receiving the 'ideal service'. Indeed all were very positive about their child, family adjustment and the services provided. Only 25% of the control group expressed similar levels of satisfaction and the criticism of the rest were the same as in previous surveys. All of the four families from the "intervention" group who failed to be told in the 'ideal manner' expressed dissatisfaction and one embarked on having the infant fostered. This highlighted the failure even in the 'ideal service' to have a written policy for all concerned staff and applicable, irrespective of individuals.

The small sample size and focus on a single condition (Down's Syndrome) caution against over-generalising the results of this study. But it does indicate that much of the expressed dissatisfaction is a direct result of poor practice.

This contention is supported by several surveys which have indicated some reduction of expressed dissatisfaction by parents over the years (Cunningham et al., 1984; Pueschel, 1985; Sloper & Turner, 1993a). More parents appear to be given the diagnosis sooner, together and in a more sympathetic manner. Using a multivariable design which assessed many aspects of the families, Sloper and Turner (1993a) also found that parental satisfaction was significantly associated with the procedural aspects of being given the diagnosis but not with internal parental characteristics such as their personality and styles of coping.

Further, if parent dissatisfaction is related to internal pathological factors associated with having a child with a disability, one would expect it to be found across situations regardless of variation in services. Wishart et al. (1993) compared two regional pre-school services for families with children with Down's Syndrome. Higher satisfaction was reported in one region which provided better co-ordination, access to information and support and used a link person or key worker to mediate between family and services. In a study of families with children with physical disabilities, Sloper and Turner (1991) found no association between satisfaction with disclosure and satisfaction with later community services. It does not seem therefore that there are parents who are satisfied with any service, but that parents do make selective judgements about the quality of service.

Thus it does appear that parental observations and criticisms are reliable and are specific to situations. As such, they should not be dismissed but used to develop good practice. When they are applied, this reduces the trauma and distress experienced by parents around the time of disclosure and facilitate co-operative parent-professional relationships.

Understanding the values of parents

It is worth noting that the values of the professional telling the parents may not be the same with regard to certain disabilities or abnormalities, as those of the parents. The professional therefore should not always assume that the news is 'bad' and needs to be 'broken', since this negative conception may not be totally shared by the parents, and anyway may not be helpful in setting the tone for the interaction with them. It has been demonstrated that professionals are often more negative about the prognosis than the scientific medical evidence justifies. It would be unfortunate if they added yet more of a negative bias about the disability or abnormality, by imposing negative values not shared by the parents.

Recommendations for Good Practice

A set of common guidelines has emerged from the research, the first hand experience of practitioners, and from working groups of parents themselves. But they are guidelines and not recipes to be imposed in all circumstances. They should be applied sensitively and with flexibility in meeting the unique requirements of

each family situation. A basic principle underlying the whole procedure is respect for the child, the parents and family and a conscious effort by practitioners to develop positive frameworks for working with parents generally (Cunningham & Davis, 1985b). The recommendations are categorized into structural procedures, manner of telling and content of interviews. Although the suggested structural procedures are set out first, research indicates that the latter two are probably the most important.

Structural Procedures

1. Parents should be told as soon as possible when a disability is diagnosed or suspected

Time is not the critical factor. There are situations where some delay is appropriate, for example, when a birth is difficult or when there are medical complications. As noted earlier, parents readily accept such explanations for delay. There are also instances of complaints of being told too soon, for example, immediately following a Caesarian birth when parents just needed to recover.

The principle is to avoid situations where professionals withhold information from parents. Often when hospital staff recognise a disability, their behaviour and that of others alters. Many parents are aware of this and begin to suspect something is different about the baby or themselves (Cunningham & Sloper, 1977). Staff often have to give false assurances that all is well which parents later recognize as 'lies' and hiding the truth.

The issue of what constitutes a suspicion and how and when to share it with parents is frequently noted by professionals. My view is that when the professional or the parent has strong enough concerns to take some further action to test their hypothesis, this is a suspicion and should be shared.

In the case of parents of children with no immediately obvious disability, suspicions usually begin when they do not appear to be developing like other children (or the parents' concept of normal development). The literature on 'evolving diagnoses' or 'uncertain aetiologies' refers frequently to complaints by over 50% of parents about having their worries dismissed and being treated as 'neurotic' (McKay & Hensey, 1990). The majority of parents are in favour of being given information as soon as possible, even if it is only based on professional suspicions (Nurse et al., 1991). Dismissing their concerns about their child is no way to start a supportive relationship.

2. Parents should be told with their partner/spouse or a friend or relative

The principle is that most people cope better with the support of the significant others in their lives. If telling the news inevitably causes problems for the teller, why place parents in this vulnerable position? Having to tell another, places the parent in the position of having to recall facts with a certainty of confidence they are unlikely to have.

3. The right to privacy should be respected

They should be told in a private place free from interruptions and the presence of 'onlookers' such as students or nurses who have no direct role in the support.

4. The baby or child should be present

This particularly concerns disclosure of disability in the new baby. Having the child present allows the professional to convey value and worth by touching and referring to the baby. Exclusion can convey that there is something to hide or avoid.

5. Schedule sufficient time

Many parents complain that they were told in a hurried way and not given time to ask questions or think about what to ask. This again implies avoidance. Giving people time conveys respect and the opportunity to establish some control over what is happening to them. Giving sufficient time is perhaps the most important structural factor.

6. Have a colleague present

This recommendation mainly concerns instances when the teller is unlikely to be able to act as a key-worker in the overall management of supporting families at this time. The person should have a defined role which is conveyed to the parents. It may be a senior nurse in the maternity unit who will ensure that other staff are aware of what the parents were told and has the responsibility for managing continuity of support (Spain & Wigley, 1975). It may be a specialist who works in the community and provides ongoing support (Cunningham et al., 1984). In some cases it is a trained person from a voluntary society - often a parent. The presence of this person strongly emphasizes to

the parent that the disclosure interview is merely the beginning of a supportive process and that there are positive things to be done. This person can make notes of the information given which are then typed and given to parents later. They should give particular attention to parent questions and key points of information conveyed, and tell parents these will be followed up.

If there are doubts about the parents' ability to speak the language of the teller, an interpreter should be present, not just for the disclosure interview, but for later discussions with the key-worker. Written information should also be in a language familiar to the parent.

7. Arrange a second interview between the parents and the teller within 24 to 48 hours

This acknowledges that parents are unlikely to assimilate information efficiently at this time and reduces the pressure on them to think up questions or remember everything. It is quite useful to ask them to write down questions or concerns that come into their head for discussion at later meetings.

8. Provide parents with leaflets or written information

Written information enables parents to review facts in their own time, share it with other family members and keep it for reference. We found 90% of parents wanted a pamphlet at the time of disclosure (Cunningham & Sloper, 1977). Quine and Pahl (1989) produced a booklet about local and national services which reduced dissatisfaction rates from 47% to 18%. Careful consideration must be given however to the format and readability of such material (Ley, 1982). The use of the Flesch readability and interest formulae (Flesch, 1948, 1949) have shown that much written information is too difficult for a large proportion of the population (Reed et al., 1993) but that it can be used to improve texts for parents (Sturmey, 1990). The content also needs further careful consideration. From discussion groups with parents, we found many did not want very reassuring pamphlets with happy family photographs at the initial disclosure. They felt this was not compatible with their initial reactions and feelings that they may not cope and prevented them having time to work through their own feelings. They felt the first pamphlet should focus on such feelings and the way people come to terms with them. Thus one needs to judge carefully the appropriate information in terms of the changing adjustment process which the parents are working through

at this time. A number of publications for parents are available on specific problems, such as Down Syndrome (Cunningham, 1985).

9. Following the disclosure, parents should be given a private place to be with each other

This enables the parents to talk and to support each other at this time.

Manner of Telling

This appears to be a critical factor and high on the list of parent demands. For example Sloper and Turner (1993a) conducted a very detailed multivariate study of 103 parents of children with severe physical disability. They found that 40% of parental dissatisfaction related to the manner of telling and 20% to lack of information or opportunities to ask questions. These factors over-rode all others including the structural procedures.

Parents want to be told:

1. *Honestly, and with uncertainties acknowledged,*
2. *In a straightforward way, without embarrassment or hedging.*

There is very little literature on how this is best done or the words to use. Some parents and professionals prefer a short lead up to the final statement and naming of the diagnosis but there is a danger that this can be seen as avoidance. In our 'ideal' model, the paediatrician varied his words along a similar pattern. For example 'Hello, I'm Dr, the baby specialist. I have been examining (child's name if possible and touching or holding baby) and have found several features (some things) which are important. (Pause). It is suggested he/she is what we call a baby with Down's Syndrome: Do you know what that is? (Pause) ...'

It is probably best to come straight to the point and to avoid conveying negative values such as 'I'm sorry to have to tell'. Once the doctor has some indication of parental reactions he can then judge how to continue.

3. *Told with warmth and understanding.*
4. *Explanations should be clear and not overly technical.*

Details can be given later and in written format.

5. *Parents should be invited to ask questions.*

This is not just about asking if the parents have any questions at the end of a professional statement. It is about encouraging a dialogue and may include suggesting some areas in which they may have questions. Clearly how this is done demands great sensitivity and basic counselling skills, such as active listening, paraphrasing and summarising.

Content of interview

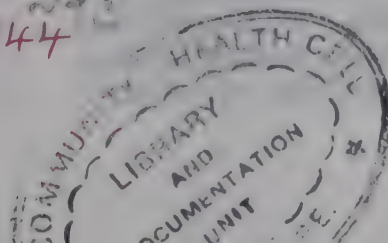
There is a lack of literature and overall consensus about the information needed by parents in the first and following interviews. The key guideline is that parent adjustment is a process of cognitive re-construction. Many parents will experience a sense of loss or grief for their fantasy perfect child who they were expecting and they may need to mourn. Most experience a great uncertainty about their feelings, their competence and the future. They need information in order to understand and make sense of what is happening and how to plan and manage their lives.

Taylor (1983) describes a theory of cognitive adaptation with three key elements common across many such events.

- * A search for a meaning in the experience - What caused it? What does it mean for my life now?
- * The need to regain mastery over the event, and control one's life generally - What can I do to manage the situation?
- * An effort to enhance one's self-esteem, usually through social comparisons with others.

Hence the need for access to information from accurate sources, sharing feelings with significant others - family, friends and other parents of children with similar disabilities. Thus the primary aim of the early support for parents is to help them make sense of what is happening by exploring such questions as:

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<p>What is the diagnosis? What is the disability? What sort of child can I expect?</p>	<p>This is about re-structuring a model of the child.</p>
<p>Why did it happen? Who am I to have such a child? Why do I feel the way I do about the child and what has happened?</p>	<p>This is about re-structuring a model of oneself and one's parenting role.</p>
<p>What effect will it have on the family? How do others react to the child? What can I/we do to help?</p>	<p>This is about developing a model of disability as well as practical strategies.</p>

Most first interviews will need to include:

*1. Accurate information about the diagnosis
and the disability*

The two aspects can be confused. Parents need to know what the diagnosis is and, for many, how it was made. In a sense they need to question the validity of the information. This is often reflected in their demand for second opinions or proof which should not be interpreted as questioning the competence of the professional. Related to this is that most professionals and many parents feel that such a diagnosis should be given by a person seen as the one with the training to make such a diagnosis, usually a paediatrician, although for evolving diagnoses or learning disability it may be a psychologist or educator. It is important therefore for the professional to share with parents the information on how the diagnosis was made.

Similarly, many parents react with shock, denial or disbelief when the diagnosis is unexpected. These are natural coping strategies rather than pathological reactions. The parents are aware that the information has implications beyond their current knowledge and need time and distance in order to begin to re-construct their ideas. Parents also need to know what the diagnosis actually means. Over 80% of parents are reported as having little information about the most frequent conditions such as Down's Syndrome or Cerebral Palsy (Murdoch, 1983). Many complain that they were mainly given a label such as *mentally retarded* with no explanation about what this meant in terms of the child's needs and possible levels of progress.

Others note that the information was largely medical, whereas most parents need to know if the child will walk, talk, and so on. They need a sense of the diagnosis in terms that are real to them.

They need accurate information, particularly about how the child may progress. All too often parents complain that the information given was overly negative and left them with little hope (Kelly & Melonascino, 1975). Again this is not just a parental impression. **Several studies have shown that whilst professional attitudes to disability may have become more positive, their expectations for the child's progress are usually pessimistic and lower than the progress actually achieved in samples of children with disability** (Foreman & Ward, 1986; Murdoch & Anderson, 1990). Low expectations of professionals have been shown to adversely affect the care made available to the child (Silverman, 1985; Wolraich et al., 1991).

*2. Clear statements on what can be
offered to assist the child and family and
follow-up procedures*

Parents need to leave the interview with the knowledge that support is available, the time of the follow-up interview and the name of the key worker who will liaise with them. At this time or shortly after, they also require written information on the condition and the available support within the hospital and community, including local and national voluntary associations.

3. *The offer to introduce parents to another parent of a child with a similar condition*

Around half the parents in our studies would have liked to meet similar parents quite soon after disclosure. The majority like to know that this is possible and take up the offer within the first months. Most find the experience very supportive.

4. *The offer to tell other members of the family the diagnosis or meet with them to answer questions*

It is important to remember that each time parents are informed of a diagnosis, they have to inform other family members and friends who in turn have to tell others. Helping parents to do this has received little formal attention but guidelines are appearing (McConachie, 1991). By offering to assist, the professional acknowledges this and opens up the issue for discussion, for example, 'How might the parent tell the other children?'. Grandparents play a key role. Waisbren (1980) found that fathers experienced less difficulties with adjusting to the diagnosis when they felt supported by their parents. Grandparents also have to adjust to their grandchild having a disability and to their feelings of protection for their child, the new parent. Again the issue of grandparent adjustment and their supportive role at this time is only just receiving attention (George, 1989; Seligman, 1991).

5. *Some indication that the feelings and reactions of the parents to the diagnosis, whilst unique to them, is normal and commonly experienced*

For many parents the diagnosis results in psychological distress which, as noted in the introduction, may not be easily resolved. Many practitioners tend to avoid these emotional aspects. Turner and Sloper (1992) found only one of a sample of seventeen paediatricians mentioned that this came into their approach when telling the diagnosis. Maguire and Faulkner (1988) suggest it is due to a lack of skills to handle the strong emotions which may emerge if practitioners open up this area and also a fear that probing into how the person is adjusting psychologically may do more harm than good. Following training, however, they did find that the professionals felt more able and willing to deal with this issue.

My own view is that parents should be made aware that the feelings they experience are common and normal and need to be aired. Too

often the emphasis shifts immediately to the child and learning what to do and no time is left to discuss the parents' feelings. Discussion groups with parents, months or years after the diagnosis indicate how feelings were hidden and controlled, often in order to protect the other partner (Cottrell & Summers, 1990).

The art is to communicate to parents that such feelings that they might experience are common and can be helped by discussion with each other and with staff and other parents without implying some strong pathology which requires psychological counselling. An understanding of the common reactions of parents and models of adjustment can help professionals in this task (Cunningham & Davis, 1985a).

This aspect includes the contentious issue as to whether to inform parents of newborn babies with disability about options such as fostering or adoption. From some preliminary discussions with parent groups, it appears that most feel they should be made aware of such options but that it should not be presented in such a manner as to suggest they are seen as 'rejecting parents'. To do this the professional must have a framework of the process by which parents adjust to the diagnosis and share this with the parent. Clearly these emotional aspects of the content of the first interview(s) are difficult; as yet there is little researched information to guide practice.

Organizational aspects

A key point made in most guidelines is that disclosure of the diagnosis and the immediate support given requires a carefully planned approach that encompasses all professionals involved. Despite this, a Campaign for People with Mental Handicap survey in the UK (1987) found that 82% of health authorities had no written guidelines or policy on this area. Turner and Sloper (1992) interviewed all paediatricians in a regional health authority and none was aware of any written guidelines. Six had developed informal procedures with colleagues but seventeen out of the twenty-four had relied solely on their individual practice and experience.

These studies found little evidence of training procedures for professionals although most thought training was important. However, there appear to be no follow-up studies on whether this improved practice and consumer satisfaction. Thus the current situation appears to be that disclosure and early support are largely dependent upon the individual improvisation of the professional involved. As concluded by Spain and Wigley (1975), 'Possibly the main reason why good service does not exist at

present is the fact that there is no-one designated with the overall responsibility for seeing that parents do receive the help that they need'. This is still the state of affairs.

The few studies that have compared parents of children with disability receiving supportive services and counselling in the early period following the birth, have found lower stress (Burden, 1980), reduced anxiety and depression, and increased self-concept (Antley & Hartlage, 1976) compared with control groups without such help. Other studies have indicated how the disclosure and immediate postnatal management of the parents may be critical for the developing attachment to the baby (Emde & Brown, 1978). This is not to argue that poor disclosure will necessarily have negative long-term effects on attachment. For example, in our research with a cohort of 180 children with Down's Syndrome, we found over 70% of families had strong warm attachment to the child in later years, despite a large proportion expressing dissatisfaction with disclosure. Similarly, Sloper and Turner (1991) found no relationships between satisfaction with disclosure and later measures of child attachment and satisfaction with other services.

Conclusions

Good disclosure practice prevents much distress for parents, fosters good parent-professional relationships, facilitates the attachment process and early care for the child and, when incorporated with family support services over the first years, reduces levels of anxiety and stress. It cannot be left to individual improvisation, as is commonly the case. There is sufficient information to inform professional training and to guide practical procedures and counselling, based upon an understanding of how parents react to the event.

The work must be valued and key people given the designated task of developing a written policy, co-ordinating the various elements of the support within the hospital or clinic and the community, and monitoring practice based on the experiences of parents. Policies and written information should be arrived at jointly with all key people involved, including parent representatives. Having established models of good practice based on current knowledge, we should be in a position to carry out longitudinal evaluations.

These should throw more light on key issues such as the content of information in terms of different family characteristics and the nature of the disability; the pace and formats of providing such information; the varying needs and roles of different family members; the structural organization of services, and staff training.

Fundamental to this is that all involved should share a positive and valuing conception of disability. They should avoid negative and pathological models and recognize that many of the assumed problems result from social factors such as poor services and inadequate support and provision.

The key organisational aspects are:

1. **The establishment of a person with overall responsibility to develop and maintain good practice.**
2. **Written procedural guidelines.** These must include procedures internal to the hospital or clinic focusing on the immediate aspects of the disclosure and procedures to ensure co-ordination with other services, for example, letters to the family practitioner, social services, schools, and so on, as appropriate to individual cases.
3. **Training of all staff in basic skills and knowledge about procedures and parent needs.**
4. **Regular review meetings of all staff in order to monitor procedures and ensure that all share the same views and approaches.** This provides for a continuity of approach to families and prevents the common problem of giving conflicting advice.
5. **Ensuring that the service is valued.** Initiating change and good practice demands that all of the key personnel involved believe it to be of value and can support their claim. The evidence reviewed above shows that much trauma and distress can be reduced and that good practice facilitates parent-professional relationships. This is sufficient justification to implement better practice.

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LEARNING MODULE

Introducing parents to their abnormal baby

The two papers included on this topic by Pearse and by Cunningham are written from a UK perspective. They need to be interpreted with caution by those working in other countries. The general principles however are certain, such as the need to respect the child and the parents, as well as the need for a policy and clearly outlined procedure to follow when the news has to be given. It is probably worthwhile to ask parents from a support group and/or others who have had to receive such news, to help in formulating a learning module that would be appropriate for the local setting. Students however, should not think that good practice in disclosing the news is all that is needed. This is just a first step which should be followed by appropriate support provided within the framework of the health and social services as well as contact with voluntary organizations coordinating support groups.

This material describes the problems posed by having to tell parents that their baby is abnormal and gives methods for doing this.

At the completion of the module: 1) The student will know how parents may react to the news that their baby is abnormal, 2) The student will be able to explain to parents that their baby is abnormal in a sensitive way. The methods used are:

1. The student will read the written material - the papers by Dr Richard Pearse and Cliff Cunningham.
2. (a) The students will form small groups with one student taking the role of the informing doctor, two students being the parents and the remainder being observers (the baby should be represented by a doll).
(b) The tutor will give the "informing doctor" a scenario to carry out, and may suggest to the parents various styles of reacting.
(c) After the doctor has informed the parents, the observers will provide feedback to him/her on the way it was done, using the following checklist.
 - * The way the "doctor" introduces himself to the parents if not already known to them.
 - * Non-verbal behaviour in the interview (eye contact, facial expression, etc).
 - * Introduction of the subject to the parents.
 - * Balance between optimism and pessimism, providing opportunity for hope.
 - * Did doctor try and elicit guilt/feelings that parents may be to blame?
 - * Did doctor say enough but not too much?
 - * Did doctor handle letting parents see baby (if deformed) sensitively?
 - * Did doctor provide enough information about the condition (this will depend if "doctor" knows what the condition is immediately)?
 - * Did doctor explain adequately and realistically about how help could be made available?
 - * How did the doctor handle the parents' emotion?
 - * Was the overall way that the doctor talked to the parents sensitive and caring?
- (d) Other students now take the role of doctor. Each role play should take no more than 5 minutes, with 5 more minutes being allowed for the parents and observers to provide feedback.
4. The tutor should arrange that parents of abnormal children come to meet with students to describe how they reacted to the news, what their feelings were and how these have changed over time. The parents should also describe how they were told, what they found good and bad about how it was done, how they think it should be done. They could also talk about the kind of help they have received since, but more particularly about what could have been explained to them at the time they were first told, in order to help them in obtaining the best support later.
5. This module should serve primarily to sensitize medical students to the issues involved. They are unlikely to have to actually tell parents the bad news, although they may be involved as part of the support team. The module should therefore be repeated in postgraduate courses for obstetricians and paediatricians. It is these latter who are key figures in ensuring good practice.

